Remarks by
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April 15 is always a big day in the life of American taxpayers as they pay all taxes due to the government. But this year, there is the possibility that the government might give something back for a change – something even more precious than money. By the close-of-business the previous day, April 14th, we will know whether the Secretary of Health and Human Services has been willing to give Americans back their privacy.

Unfortunately, Americans have reason to be anxious about whether their privacy will be left standing in April. Although regulations promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to protect medical privacy are scheduled to go in to effect by then, Secretary Tommy Thompson recently opened up the final rule – issued on December 20, 2000 – to a new 30-day comment period which ends on March 30, just two weeks before the effective date. By taking this action, he has re-ignited intense industry opposition to these privacy standards and has raised the possibility that this rule will be killed outright or delayed to death

This would be outrageous. We stand here before you with Chris Koyanagi of the Bazelon Center – representing over 35 mental health groups – to say that medical privacy is just too important to put on hold. Over 40 Members of the House and Senate have signed this letter to Secretary Thompson urging him not to waver. The time has come to Preserve and Protect the Privacy of medical records.

In the past Americans thought their medical records were locked safely away in a metal filing cabinet in the local doctor's office – the keys held by a trustworthy nurse whose concern for your privacy rivaled your mother's.

But today, both your mother and that nurse are increasingly out of the loop. Your medical information is being converted from paper to electronic form, so that with the stroke of a key or the click of a mouse this information can be compiled, cross-checked, and easily accessed, not just by those with a legitimate purpose – the "privacy keepers" – but also by those who pirate privacy – the "information reapers" and "privacy peepers."

HIPAA was designed to improve health care in this new, electronic age. And the privacy regulation that it mandated was designed to help replace the security of the locked filing cabinet in your local doctor's office.

This regulation provides new federal medical privacy rights for Americans and new restrictions on how medical information can be used and disclosed. And it applies to electronic, paper and oral communications – an improvement from the proposed rule which only covered electronic information.

These new rights provided by the HIPAA privacy rule include:

- The right to know how your medical records will be used, by whom and for what purpose.

- The right to give your permission to have your medical information used or disclosed.

- The right to inspect, copy, and amend your medical records.

- And the right to request restrictions on the use and disclosure of medical information.

The rule also creates new boundaries for medical information:

- For the first time, health information may not be used without explicit consent by employers to make personnel decisions.

- For the first time, disclosures of medical information must be limited to the "minimum amount necessary" for the purpose of disclosure. Transfer of medical records for purposes of treatment would continue unimpeded, since physicians need full access to the full record in order to provide high quality care. But a new culture of confidentiality would follow these records whenever they began to drift out from under the halo of primary care.

- And for the first time, the rule creates an incentive for helath plans and providers to create and use de-identified information.

It's been a long road to this federal medical privacy standard. HHS presented Congress with recommendations for a medical privacy law back in 1997. When Congress failed to meet its deadline for comprehensive health privacy legislation, HHS moved forward with promulgating a medical privacy regulation as mandated by HIPAA. HHS issued its proposed rule in November 1999 followed by an extended comment period resulting in 52,000 comment letters. HHS then assigned over 70 individuals from 12 agencies to review, digest and incorporate these comments over a ten month period and finally issued its final rule.

HIPAA required that the privacy rule be implemented in February 2000, we're over a year late.

This rule does not complete the job of privacy protection by any means. There were statutory limitations on HHS's authority that makes this rule imcomplete, and loopholes remain that need to be addressed by Congress. But privacy advocates everywhere recognize the value of this rule as an "Island of Protection" in an "Ocean of Electronic Profiling". We need to hold on to what we have before we start working on the rest.

When we say it would be a "tragedy" to lose this rule, we don't use that word lightly. It was Shakespeare himself who wrote:

> He "who steals my purse steals trash – twas mine, 'tis his
> An has been a slave to thousands;
> But he that filches from me my good name
> Robs me of that which not enriches him,
> And makes me poor indeed!"

We urge Secretary Thompson to do the right thing and move forward with this his long-awaited federal health privacy standard.

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